



## **END OF LIFE CARE BIBLIOGRAPHY JUNE 2003**

1: Age Ageing. 2003 Jan;32(1):117-8.

Comment on:

Age Ageing. 2002 Jan;31(1):29-36.

Palliative care is an important aspect of heart failure management.

Athavale NV.

Publication Types:

Comment

Letter

PMID: 12540361 [PubMed - indexed for MEDLINE]

2: Am J Hosp Palliat Care. 2003 May-Jun;20(3):201-4.

Developing end-of-life interdisciplinary programs in universitywide settings.

Gelfand DE, Baker L, Cooney G.

Department of Sociology, Wayne State University, Detroit, Michigan, USA.

Interdisciplinary programs in end of life are widely discussed as valuable, particularly approaches to end-of-life care. Despite this emphasis, interdisciplinary programs have not been easy to implement. In universities, the implementation of interdisciplinary programs encounters administrative obstacles, including credit for the time spent in these group efforts and "ownership" of interdisciplinary courses (IDCs). This article details the process of development and the activities of an end-of-life interdisciplinary program at one urban university with a major medical center. The issues faced in the first year are examined. These included trust, group identity, and communication. The lessons from the first-year activities are presented and efforts of the second year described.

PMID: 12785041 [PubMed - in process]

3: Am J Hosp Palliat Care. 2003 May-Jun;20(3):191-200.

Characteristics of dementia end-of-life care across care settings.

Volicer L, Hurley AC, Blasi ZV.

Geriatric Research Education Clinical Center, E. N. Rogers Memorial Veterans Hospital, Bedford, Massachusetts, USA.

End-of-life care for persons with dementia in different care settings was retrospectively surveyed. In this sample, care recipients receiving hospice care and pain control stayed at home longer and were more likely to die at home. Psychiatric symptoms increased caregiver burden and were the most common reason for admission to an institution, and psychiatric care was associated with longer stay at home. Presence of advance directives decreased hospital stay and increased the likelihood of dying in a nursing home. Care recipients dying at home had fewer symptoms and less discomfort than care recipients dying in other settings. These results indicate that quality end-of-life care can be provided at home and is facilitated by hospice programs, effective pain control, and psychiatric care.

PMID: 12785040 [PubMed - in process]

4: Am J Nurs. 2003 May;103(5):52-60.

Improving the Quality of End-of-Life Care.

Virani R, Sofer D.

While no one can define a good death in absolute terms, it's possible to improve the quality of care during the final days of a patient's life. The seventh in a series on palliative nursing care.

PMID: 12759603 [PubMed - in process]

5: Am J Respir Crit Care Med. 2003 May 15;167(10):1302-3.

Comment on:

Am J Respir Crit Care Med. 2003 May 15;167(10):1310-5.

Perceptions, confessions: a systems response is needed.

Morris AH.

Publication Types:

Comment  
Editorial

PMID: 12738596 [PubMed - indexed for MEDLINE]

6: Amyotroph Lateral Scler Other Motor Neuron Disord. 2002 Dec;3(4):182-5.

Models of care for motor neuron disease: setting standards.

Hardiman O, Traynor BJ, Corr B, Frost E.

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Models of care for people with motor neuron disease (MND) must be designed in a patient-centered format, with an in-built flexibility and responsiveness that reflect the evolving nature of the condition. Diagnosis should be made as early as possible. Patients should have early access to centres with specialist knowledge of amyotrophic lateral sclerosis (ALS). Services should be flexible and responsive to the needs of the patient, and operate to best advantage when functioning as a coordinated team that cross-refers internally. Patients with ALS should be empowered to make rational end-of-life decisions based on maximizing quality of life and maintaining dignity. All models of care should be designed to cater for the sudden change from health to chronic illness, and should aim to provide a core of specialties that are patient-oriented, flexible and responsive. Ultimately, models of care should be assessed based on their outcomes.

Publication Types:

Review

Review, Tutorial

PMID: 12710506 [PubMed - indexed for MEDLINE]

7: Ann Intern Med. 2003 May 6;138(9):743-6.

Resolution of futility by due process: early experience with the Texas Advance Directives Act.

Fine RL, Mayo TW.

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Every U.S. state has developed legal rules to address end-of-life decision making. No law to date has effectively dealt with medical futility--an issue that has engendered significant debate in the medical and legal literature, many court cases, and a formal opinion from the American Medical Association's Council on Ethical and Judicial Affairs. In 1999, Texas was the first state to adopt a law regulating end-of-life decisions, providing a legislatively sanctioned, extrajudicial, due process mechanism for resolving medical futility disputes and other end-of-life ethical disagreements. After 2 years of practical experience with this law, data collected at a large tertiary care teaching hospital strongly suggest that the law represents a first step toward practical resolution of this controversial area of modern health care. As such, the law may be of interest to practitioners, patients, and legislators elsewhere.

PMID: 12729429 [PubMed - indexed for MEDLINE]

8: Ann Intern Med. 2003 May 20;138(10):812-8.

Advance care planning for fatal chronic illness: avoiding commonplace errors and unwarranted suffering.

Lynn J, Goldstein NE.

Center for Palliative Care Studies, The Washington Home Center for Palliative Care Studies and RAND Health, Washington, DC 20016, USA.  
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Patients with eventually fatal illnesses often receive routine treatments in response to health problems rather than treatments arising from planning that incorporates the patient's situation and preferences. This paper considers the case of an elderly man with advanced lung disease who had mechanical ventilation and aggressive intensive care, in part because his nursing home clinicians did not complete an advance care plan and his do-not-resuscitate order did not accompany him to the hospital. The errors that led to his hospitalization and his unwanted treatment there demonstrate how the ordinary lack of advance care planning is deleterious for patients who are nearing the end of life. We discuss serious, recurring, and generally unnoticed errors in planning for care near the end of life and possible steps toward improvement. Repairing these shortcomings will require quality improvement and system redesign efforts, methods familiar from patient safety initiatives. Reliable improvement will also require making it unacceptable for clinicians to fail to plan ahead for care during fatal chronic illness.

PMID: 12755553 [PubMed - indexed for MEDLINE]

9: Ann Intern Med. 2003 May 20;138(10):848-9.

Any oasis will do.

Hislop JO.  
jdhislop@peoplepc.com

PMID: 12755560 [PubMed - indexed for MEDLINE]

10: Ann R Coll Physicians Surg Can. 2002 Mar;35(2):107-8.

Quality end-of-life care: the rights of every Canadian.

Reichenfeld HF.  
hasreich@systemweb.com

PMID: 12755131 [PubMed - in process]

11: Annu Rev Med. 2003;54:53-72. Epub 2001 Dec 03.

Update in palliative medicine and end-of-life care.

Abraham JL.

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Palliative medicine includes clinical palliative care, education, and research that focus on the quality of life of patients with advanced disease and their families. The domain of palliative medicine is the relief of suffering: physical, psychological, social, and spiritual. Palliative medicine and care for patients at the end of life and their families include the following key components: compassionate communication; exploration of patient and family values and goals of care; expert attention to relief of suffering; management of pain, depression, delirium, and other symptoms; awareness of the manifestations of grief; and sensitivity to the concerns of bereaved survivors.

Publication Types:

Review

Review Literature

PMID: 12525669 [PubMed - indexed for MEDLINE]

12: Annu Rev Med. 2003;54:185-96. Epub 2001 Dec 03.

Standards of care in geriatric practice.

Luchi RJ, Gammack JK, Narcisse VJ 3rd, Storey CP Jr.

Department of Medicine, Baylor College of Medicine, Houston, Texas 77030, USA. rluchi@bcm.tmc.edu

We propose a set of standards to aid the physician in the care of older patients. These standards are based on the practical experiences of our own group and of others with years of clinical practice in geriatric medicine. The standards also reflect the guidelines, position papers, and deliberations of various organizations concerned with the care of older people. This article does not discuss specific illnesses or the common geriatric syndromes. The proposed standards cover comprehensive care and assessment, especially of vulnerable elders and prevention of disease and disability. We also propose standards for facilitation of care across the health service continuum, care of the nursing home resident, and palliative and hospice care.

Publication Types:

Review

Review, Tutorial

PMID: 12359825 [PubMed - indexed for MEDLINE]

**Library Program Office**  
**Office of Information**  
Veterans Health Administration

13: Arch Intern Med. 2003 May 12;163(9):1084-8.

Prevalence and structure of palliative care services in California hospitals.

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**BACKGROUND:** Most Americans die in hospitals where shortcomings in end-of-life care are endemic. Hospital-based palliative care services can improve the care of these patients, yet there are limited data regarding the availability of such services. We sought to determine the prevalence of palliative care services in California hospitals. **METHODS:** We conducted a cross-sectional survey of a random sample of 25% of all California hospitals. We recorded the percentage of hospitals reporting current or planned palliative care consultation services or inpatient palliative care units. **RESULTS:** We collected data from 107 (96%) of 112 hospitals. Only 17% of hospitals have a palliative care consult service, and 6% have an inpatient palliative care unit. Nearly all services are multidisciplinary. Twenty percent of hospitals have a contract to provide inpatient hospice beds, 19% have an outpatient-based hospice service affiliated with the hospital, and 74% offer bereavement services. Half of all palliative care services are funded exclusively by the hospital. Thirty-eight hospitals (36%) reported an interest in developing palliative care services. **CONCLUSIONS:** Few California hospitals currently have palliative care services, though more express interest in developing them. Bereavement and hospice services are more common and offer opportunities for increasing the number of palliative care services in hospitals. Further studies are needed to characterize palliative care services more fully and to assess the quality of care provided by these services.

PMID: 12742807 [PubMed - indexed for MEDLINE]

14: Arch Phys Med Rehabil. 2003 Apr;84(4 Suppl 2):S23-8.

Threats to "informed" advance directives for the severely physically challenged?

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The neuromuscular diseases, such as infantile spinal muscular atrophy, Duchenne's muscular dystrophy, and amyotrophic lateral sclerosis, are widely considered to be terminal illnesses. However, as with many neuromuscular and neurologic diseases, morbidity and mortality are caused by dysfunction of inspiratory, expiratory, and bulbar musculature. This article will discuss how inspiratory and expiratory musculature can be supported by simple, noninvasive

means that are rarely considered when, as with the general population, individuals with disabilities are counseled about advance directives. Failure to use noninvasive aids almost invariably results in respiratory failure, intubation, and tracheostomy or death. When noninvasive aids are available, invasive measures referred to in advance directives (eg, intubation) are often needed only temporarily. Yet, ill-informed patients are often advised to refuse intubation and die or to be intubated and left to decide whether to undergo tracheostomy for long-term ventilatory support. Further, despite severe disability, ventilator users with neuromuscular disease report normal life satisfaction. Health care professionals, on the other hand, tend to ignore the patient's life satisfaction and consider quality of life measures not designed for the disabled to justify withholding life-saving interventions. Advance directives, although sometimes appropriate for patients with irretractable pain and advanced cancer, are inappropriate for patients with severe disability because of muscle weakness, and virtually no patients are appropriately counseled about all therapeutic options.

Publication Types:

Review

Review, Tutorial

PMID: 12692768 [PubMed - indexed for MEDLINE]

15: BMC Palliat Care. 2003 May 13 [Epub ahead of print].

Sedation in palliative care - a critical analysis of 7 years experience.

Muller-Busch HC, Andres I, Jehser T.

**Background**The administration of sedatives in terminally ill patients becomes an increasingly feasible medical option in end-of-life care. However, sedation for intractable distress has raised considerable medical and ethical concerns. In our study we provide a critical analysis of seven years experience with the application of sedation in the final phase of life in our palliative care unit.**Methods**Medical records of 548 patients, who died in the Palliative Care Unit of GK Havelhoehe between 1995-2002, were retrospectively analysed with regard to sedation in the last 48 hrs of life. The parameters of investigation included indication, choice and kind of sedation, prevalence of intolerable symptoms, patients' requests for sedation, state of consciousness and communication abilities during sedation. Critical evaluation included a comparison of the period between 1995-1999 and 2000-2002. **Results**14.6% (n=80) of

the patients in palliative care had sedation given by the intravenous route in the last 48 hrs of their life according to internal guidelines. The annual frequency to apply sedation increased continuously from 7% in 1995 to 19% in 2002. Main indications shifted from refractory control of physical symptoms (dyspnoea, gastrointestinal, pain, bleeding and agitated delirium) to more psychological distress (panic-stricken fear, severe depression, refractory insomnia and other forms of affective decompensation). Patients' and relatives' requests for sedation in the final phase were significantly more frequent during the period 2000-2002. **Conclusion**Sedation in the terminal or final phase of life plays an increasing role in the management of intractable physical and psychological distress. Ethical concerns are raised by patients' requests and

needs on the one hand, and the physicians' self-understanding on the other hand. Hence, ethically acceptable criteria and guidelines for the decision making are needed with special regard to the nature of refractory and intolerable symptoms, patients' informed consent and personal needs, the goals and aims of medical sedation in end-of-life care. Key words: terminal sedation - palliative care - ethics - symptom control - attitudes - advance directives

PMID: 12744722 [PubMed - as supplied by publisher]

16: Br J Nurs. 2003 Mar 13-26;12(5):272.

Hospice care is turning into acute care.

Woods K.

Publication Types:  
Letter

PMID: 12685436 [PubMed - indexed for MEDLINE]

17: Buffalo Law Rev. 2000 Winter;48(1):83-173.

The legal bounds of physician conduct hastening death.

Cantor NL, Thomas GC.

Rutgers University School of Law, Newark, New Jersey, USA.

PMID: 12715817 [PubMed - indexed for MEDLINE]

18: Can Fam Physician. 2003 Apr;49:492-5.

Can lack of communication kill?

Hotson K.

PMID: 12729246 [PubMed - indexed for MEDLINE]

19: Can Nurse. 2003 Mar;99(3):27-31.

Primer. End-of-life care.

McGoey A.

Pain and Symptom Management Team, Community Care Access Centre, Thunder Bay, Ontario.



PMID: 12696201 [PubMed - indexed for MEDLINE]

20: Can Oncol Nurs J. 2003 Spring;13(2):131-2.

Determining the process of providing quality end-of-life care to hospitalized adult medical patients: the perspectives of nurses.

Thompson G.

University of Manitoba.

PMID: 12793159 [PubMed - in process]

21: Clin Geriatr Med. 2003 Feb;19(1):225-39.

Managing respiratory symptoms at the end of life.

Jacobs LG.

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Early and clear discussion and articulation of preferences about interventions with increasing burdens and diminishing benefits is helpful in identifying the goals of care and planning management for patients who have unremitting terminal illnesses. The development of respiratory symptoms such as dyspnea, cough, and hiccups is common and can often be anticipated. Aggressive evaluation and treatment should be pursued and offered to palliate symptoms at the end of life.

Publication Types:

Review

Review, Tutorial

PMID: 12735124 [PubMed - indexed for MEDLINE]

22: Crit Care Med. 2003 May;31(5):1551-9.

Surgeons, intensivists, and the covenant of care: Administrative models and values affecting care at the end of life-Updated.

Cassell J, Buchman TG, Streat S, Stewart RM, Buchman TG, Streat S, Stewart RM.

CONTEXTEnd-of-life care remains a challenging and complex activity in critical care units. There is little information concerning the influence of administrative models of care delivery on end-of-life care.OBJECTIVETo compare and contrast end-of-life care delivery in intensive care units using "semiclosed," "open," and "closed" administrative models.DESIGNEthnographic

study of three critical care units.SETTINGUniversity hospitals in the United States and New Zealand.SUBJECTSApproximately 600 physicians, nurses, allied health personnel, patients, family members, and friends.MEASUREMENTS AND MAIN RESULTSEthnographic observations were made at three sites for 75, 3, and 10 wks, respectively. Eighty end-of-life care episodes were observed. The interactions among care personnel and families varied according to the administrative model, depending on whether surgeons or intensivists had primary patient responsibility. This led to differential timing on the shift from "cure" to "comfort," and differential decision-making power for families.CONCLUSIONSEnd-of-life care varies according to the administrative model. When surgeons have primary responsibility for the patient, the most important goal is defeating death. When intensivists have sole patient responsibility, scarce resources are considered and quality of life is a significant variable. Discussions about improving the way end-of-life decisions are carried out in intensive care units rarely consider the administrative models and personal, professional, and national values affecting such decisions. To improve care at the end of life, we must critically examine these features.

PMID: 12771632 [PubMed - in process]

23: Crit Care Med. 2003 May;31(5 Suppl):S373-8.

Race and the intensive care unit: Disparities and preferences for end-of-life care.

Degenholtz HB, Thomas SB, Miller MJ.

PMID: 12771586 [PubMed - in process]

24: Curr Probl Surg. 2003 May;40(5):266-310.

Organ donation and treatment of the multi-organ donor.

Tuttle-Newhall JE, Collins BH, Kuo PC, Schoeder R.

Section of Transplant Surgery, Duke University Medical Center, Durham, North Carolina, USA.

Publication Types:

Review

Review, Academic

PMID: 12759693 [PubMed - indexed for MEDLINE]

25: Death Stud. 2003 May;27(4):305-15.

Comment in:

Death Stud. 2003 May;27(4):317-20.

Comment on:

Death Stud. 2003 May;27(4):295-304.

Inactivating a total artificial heart: special moral problems.

Veatch RM.

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It seems generally correct that patients (or their valid surrogates) should be able to withdraw consent for the use of the total artificial heart (TAH) just as they presently may withdraw consent for other life-prolonging technologies such as the ventilator, but lingering moral problems remain with such decisions. First, should patients be permitted to demand actual removal of the TAH rather than mere deactivation? Second, forgoing other life-prolonging technologies is normally considered "indirect" killing and is therefore judged legal (as well as moral to those who accept only indirect killing). As long as the society includes irreversible stoppage of the heart as one of the criteria for death, however, stopping a TAH will be considered direct killing, i.e., murder. To circumvent this inconsistency, society must change its conclusion that stopping other life-prolonging technologies is merely indirect killing, explicitly legalize direct killing by means of stopping a TAH, or revisit the definition of death to eliminate the cardiac standard for death from the definition of death. Assuming that the stopping of the TAH with patient or surrogate consent is acceptable, we must then face the question of whether physicians who believe the TAH is serving no purpose can unilaterally stop the device against the wishes of a patient or surrogate who believes it is still serving a worthwhile purpose. Clinicians should be presumed authoritative in determining the predicted effect of the TAH, but, if the TAH can temporarily prolong life for a patient in a way that is desired by the patient or surrogate, case law, professional society recommendation, and moral analysis all support the conclusion that the TAH must be continued even against the conscientious objection of the physician

Publication Types:

Comment

PMID: 12749375 [PubMed - indexed for MEDLINE]

26: Death Stud. 2003 May;27(4):295-304.

Comment in:

Death Stud. 2003 May;27(4):305-15.

Contemplating total artificial heart inactivation in cases of futility.

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Though currently an experimental technology, there is the potential for implantation of 100,000 total artificial replacement hearts each year in the

United States once regulatory approvals are obtained. Although these devices are intended to lengthen life and improve its quality, clinical scenarios can emerge in which the device is no longer serving these goals and termination of life support, including inactivation of the implant, must be contemplated. Although the literature is replete with guidance on the withdrawal of non-implantable therapies, such as dialysis and artificial ventilation, there has been minimal discussion involving the deactivation of implanted therapies. Here, guidance is offered regarding the withdrawal of total artificial heart therapy.

PMID: 12749363 [PubMed - indexed for MEDLINE]

27: Death Stud. 2003 May;27(4):335-54.

Death anxiety and attitudes toward the elderly among older adults: the role of gender and ethnicity.

Depaola SJ, Griffin M, Young JR, Neimeyer RA.

Auburn University--Montgomery, Montgomery, Alabama, USA.

The article investigated the relationship between death anxiety, attitudes toward older adults, and personal anxiety toward one's own aging in a group of 197 older men and women. As predicted, negative attitudes toward other older adults were predicted by personal anxieties about aging and death, and, more specifically, fear of the unknown. In addition, several distinctive anxieties were noted for particular subgroups of respondents. Older women scored higher on the Fear of the Dead subscale of the Multidimensional Fear of Death Scale (MFODS) than did men. Caucasian participants displayed higher Fear of the Dying Process than did older African American participants. Lastly, older African American participants reported higher levels of death anxiety on 3 of the subscales of the Multidimensional Fear of Death Scale (Fear of the Unknown, Fear of Conscious Death, and Fear for the Body after Death) when compared with older Caucasian participants and also tended to accord less social value to the elderly. These findings are interpreted in terms of patterns of socialization, and their implications for end-of-life care preferences are noted.

PMID: 12749378 [PubMed - indexed for MEDLINE]

28: Death Stud. 2003 May;27(4):317-20.

Comment on:

Death Stud. 2003 May;27(4):305-15.

Replying to Veatch's concerns: special moral problems with total artificial heart inactivation.

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Moral problems arise when contemplating the inactivation of total artificial heart technology: however, an ethical obligation to explant the device as part of therapy withdrawal is not one of them. Further, arguments will be presented justifying that inactivation of the device is not morally equivalent to active killing of the patient. When device inactivation is clinically and ethically warranted, this decision should not be unilaterally made by the physician but through thorough discussion with the patient (if possible), the patient's surrogate, and the medical team. Consultation with legal counsel and the hospital ethics committee may also be appropriate

Publication Types:  
Comment

PMID: 12749376 [PubMed - indexed for MEDLINE]

29: Gastroenterol Nurs. 2003 Mar-Apr;26(2):55-9.

Physician-assisted suicide.

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There are many issues surrounding the end of life. One of the most controversial is physician-assisted suicide. Because nursing is intimately involved with care of patients at the end of life in a variety of settings, it is incumbent upon nurses to be well informed on this issue. This article will examine the ethical, social, legal, political, and economic impact of physician-assisted suicide.

Publication Types:  
Historical Article  
Review  
Review, Tutorial

PMID: 12682525 [PubMed - indexed for MEDLINE]

30: Gerontologist. 2003 Apr;43 Spec No 2:76-84.

Factors that influence end-of-life care in nursing homes: the physical environment, inadequate staffing, and lack of supervision.

Kayser-Jones J, Schell E, Lyons W, Kris AE, Chan J, Beard RL.

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PURPOSE: This study investigated the physical environment and organizational factors that influenced the process of providing care to terminally ill nursing home residents. DESIGN AND METHODS: Participant observation, interviews, and event analysis were used to obtain data in two proprietary facilities. RESULTS:

The physical environment was not conducive to end-of-life care. The rooms were crowded, there was little privacy, and the facilities were noisy. Inadequate staffing and lack of supervision were among the most significant organizational factors that influenced care. Often, residents did not receive basic care, such as bathing, oral hygiene, adequate food and fluids, and repositioning. A consequence of inadequate staffing was the development of pressure ulcers; 54% of the residents had pressure ulcers; 82% of these residents died with pressure ulcers. IMPLICATIONS: Findings suggest that the nursing home environment in these two facilities, as now structured, is an inappropriate setting for end-of-life care.

PMID: 12711727 [PubMed - indexed for MEDLINE]

31: Gerontologist. 2003 Apr;43 Spec No 2:94-5.

Comment on:

Gerontologist. 2003 Apr;43 Spec No 2:85-93.

Commentary on "Lower respiratory infections in nursing home residents with dementia: a tale of two countries": dying in the nursing home.

Tuch H.

Palliative Care Resources, Hospice of the Florida Suncoast, 3324 Westmoreland Drive, Tampa, FL 33618, USA. hstuch@msn.com

Publication Types:

Comment

PMID: 12711729 [PubMed - indexed for MEDLINE]

32: Hastings Cent Rep. 2003 Mar-Apr;Suppl:S30-2.

The relevance of public health in improving access to end of life care.

D'Onofrio C, Ryndes T.

School of Public Health, University of California, Berkeley, USA.

PMID: 12762190 [PubMed - in process]

33: Hastings Cent Rep. 2003 Jan-Feb;33(1):5-6; author reply 6.

Comment on:

Hastings Cent Rep. 2002 Jul-Aug;32(4):14-21.

Physician-assisted death.

Koch T.

Publication Types:  
Comment  
Letter

PMID: 12613373 [PubMed - indexed for MEDLINE]

34: Hastings Cent Rep. 2003 Jan-Feb;33(1):6; author reply 6.

Comment on:  
Hastings Cent Rep. 2002 Jul-Aug;32(4):14-21.

Physician-assisted death.

Porter AP.

Publication Types:  
Comment  
Letter

PMID: 12613374 [PubMed - indexed for MEDLINE]

35: Hastings Cent Rep. 2003 Jan-Feb;33(1):7; author reply 7.

Comment on:  
Hastings Cent Rep. 2002 Jul-Aug;32(4):14-21.

Physician-assisted death.

Smith WJ.

Publication Types:  
Comment  
Letter

PMID: 12613375 [PubMed - indexed for MEDLINE]

36: Hastings Cent Rep. 2003 Jan-Feb;33(1):17-9.

Physician-assisted suicide: a conservative critique of intervention.

Lee DE.

PMID: 12613383 [PubMed - indexed for MEDLINE]

37: Home Healthc Nurse. 2003 Mar;21(3):150-1.

End-stage dementia: hospice offers expert interdisciplinary care for end-stage dementia.

Head B.

University of Louisville, School of Medicine, KY 40223, USA.  
barbara.head@louisville.edu

PMID: 12637817 [PubMed - indexed for MEDLINE]

38: Home Healthc Nurse. 2003 Mar;21(3):152-5.

What's new in the 2003 Joint Commission? Home care and hospice standards: part 2.

Friedman MM; Joint Commission of Accreditation on Healthcare Organizations.

mmf@mindspring.com

PMID: 12637818 [PubMed - indexed for MEDLINE]

39: Home Healthc Nurse. 2003 Mar;21(3):193-4.

Hospice and palliative care specialty certification for nursing assistants.

Martinez JM; National Board for Certification of Hospice and Palliative Nurses.

Education for Physicians on End-of-life Care Project, Northwestern University, Feinberg School of Medicine, Chicago IL 60611, USA. Jmartinez@epec.net

PMID: 12637826 [PubMed - indexed for MEDLINE]

40: Home Healthc Nurse. 2003 Apr;21(4):224-7.

Hospice or home health-which does the patient need?

Pitorak EF.

Hospice of the Western Reserve, Cleveland, OH 44119, USA.

PMID: 12695694 [PubMed - indexed for MEDLINE]

41: Int J Palliat Nurs. 2003 Apr;9(4):140.

Comment on:

Ann Intern Med. 1997 Jan 15;126(2):97-106.

J Am Geriatr Soc. 2000 May;48(5 Suppl):S214-21.



Time for non-cancer.

Connolly M.

Publication Types:

Comment

Editorial

PMID: 12734449 [PubMed - indexed for MEDLINE]

42: Int J Palliat Nurs. 2003 Apr;9(4):166-72.

Breaking bad news revisited: the push for negotiated disclosure and changing practice implications.

Arber A, Gallagher A.

European Institute of Health and Medical Sciences, University of Surrey, UK.

This article revisits the ethical, legal, professional and emotional issues involved with disclosing bad news. The authors examine the push for disclosure that has come from a number of quarters in the UK, including ethical and legal challenges, in particular the Bristol Royal Inquiry Report, professional codes of conduct, health policy and the expectations of the public. The contribution of nurses to breaking bad news is not widely discussed in the literature. With the development of new nursing roles and evidence-based practice it is timely to consider the role of nurses in this process. The article highlights some limitations with current guidelines for breaking bad news, in particular, that these guidelines tend to be constructed from a professional standpoint and lack patient-centred evidence. The issue of emotional labour and how it relates to giving bad news is discussed with respect to professional staff and patients. The article concludes by raising some practice implications, including: the importance of context and continuity; the significance of information and support; the desirable qualities of the professional; and issues to consider in determining patient preferences.

PMID: 12734453 [PubMed - indexed for MEDLINE]

43: Issues Law Med. 2003 Spring;18(3):211-37.

Quiet killings in medical facilities: detection & prevention.

Thunder JM.

Kellogg, Huber, Hansen, Todd & Evans, P.L.L.C., Washington, D.C., USA.  
thundergroup@alumni.nd.edu

Publication Types:

Legal Cases

Review

Review, Tutorial

PMID: 12693179 [PubMed - indexed for MEDLINE]

44: Issues Ment Health Nurs. 2003 Jan-Feb;24(1):45-57.

Nurse-assisted suicide: not an answer in end-of-life care.

King P, Jordan-Welch M.

University of Tennessee, Knoxville, Tennessee, USA. pking@milligan.edu

Publication Types:

Review

Review, Tutorial

PMID: 12735074 [PubMed - indexed for MEDLINE]

45: J Am Board Fam Pract. 2003 Jan-Feb;16(1):58-62.

Comment in:

J Am Board Fam Pract. 2003 Jan-Feb;16(1):78-80.

End-of-life care for a man with developmental disabilities.

Lohiya GS, Tan-Figueroa L, Crinella FM.

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**BACKGROUND:** Science can artificially maintain many essential life functions. Does such care prolong life or dying? **METHODS:** A case is described of a patient with developmental disability with unknown health care choices who was hospitalized for drug-resistant urosepsis. He developed aspiration pneumonia, deep vein thrombosis, and respiratory arrest. He required gastrostomy, tracheostomy, artificial ventilation, parenteral nutrition, hemodialysis, multiple anti-infective agents, and blood transfusions. On day 58, a bioethics committee recommended against cardiopulmonary resuscitation. On day 66, the patient's conservator concurred but required continuation of artificial ventilation. To the dismay of some caretakers, the patient continued to receive intrusive care until his death on day 104. The hospital charge was \$709,206. **RESULTS AND CONCLUSION:** Hospital care of patients with mental incapacity can be clinically and ethically challenging. End-of-life decisions can be facilitated when the patient's legal representative and physician actively advocate the patient's best interests and communicate frequently and openly. Suggestions are made for such exigencies.

PMID: 12583651 [PubMed - indexed for MEDLINE]

46: J Am Coll Surg. 2003 May;196(5):807-15.

Robert Wood Johnson Foundation Office of Promoting Excellence in End-of-Life Care: executive summary of the report from the field.

Surgeons Palliative Care Workshop.

Publication Types:

Consensus Development Conference  
Review

PMID: 12742216 [PubMed - indexed for MEDLINE]

47: J Am Geriatr Soc. 2003 Jun;51(6):789-97.

Decisions for hospice care in patients with advanced cancer.

Chen H, Haley WE, Robinson BE, Schonwetter RS.

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**OBJECTIVES:** To identify factors that may influence the decision of whether to enter a hospice program or to continue with a traditional hospital approach in patients with advanced cancer and to understand their decision-making process. **DESIGN:** Cross-sectional structured interview. **SETTING:** One community-based hospice and three university-based teaching hospitals. **PARTICIPANTS:** Two hundred thirty-four adult patients diagnosed with advanced lung, breast, prostate, or colon cancer with a life expectancy of less than 1 year: 173 hospice patients and 61 nonhospice patients receiving traditional hospital care. **MEASUREMENTS:** Hospice and nonhospice patients' demographic, clinical, and other patient-related characteristics were compared. Multivariate analysis was then conducted to identify variables associated with the hospice care decision in a logistic regression model. Information sources regarding hospice care and people involved in the hospice decision were identified. **RESULTS:** Patients receiving hospice care were significantly older (average age 69 vs 65 years,  $P = .009$ ) and less educated (average 11.9 vs 12.9 years,  $P = .031$ ) and had more people in their households (average 1.66 vs 1.16 persons,  $P = .019$ ). Hospice patients had more comorbid conditions (1.30 vs 0.93,  $P = .035$ ) and worse activities of daily living scores (7.01 vs 6.23,  $P = .030$ ) than nonhospice patients. Hospice patients were more realistic about their disease course than their nonhospice counterparts. Patients' understanding of their prognoses affected their perceptions of the course of their disease. Hospice patients preferred quality of life to length of life. In the multivariate analysis, lower education level and greater number of people in the household were associated with the decision to enter hospice. A healthcare provider first told most of those who entered hospice about hospice. Families largely made the final decision to enter hospice (42%), followed by patients themselves (28%) and physicians (27%). **CONCLUSION:** The decision to enter hospice is related to demographic, clinical, and other patient-related characteristics. This study suggests that the decision-making process for hospice care in patients with advanced cancer is multidimensional. The healthcare community may better meet the end-of-life care needs of advanced cancer patients through enhanced communication with patients and families,

including providing accurate prognoses and better understanding of patients' preferences and values.

PMID: 12757565 [PubMed - in process]

48: J Am Geriatr Soc. 2003 Apr;51(4):492-8.

The last 2 years of life: functional trajectories of frail older people.

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**OBJECTIVES:** To characterize the functional trajectories during the last 2 years of life of patients with progressive frailty, with and without cognitive impairment, and to assess whether it was possible to identify discrete functional indicators that signal the end of life. **DESIGN:** A retrospective analysis of functional trajectories during the last 24 months of life. **SETTING:** Twelve demonstration sites of the Program of All-inclusive Care for the Elderly (PACE). PACE cares for frail older people who meet criteria for nursing home placement, with the goal of keeping the patient at home. **PARTICIPANTS:** Nine hundred seventeen patients who died while enrolled in PACE. **MEASURES:** At PACE entry and every 3 months thereafter, data were collected about the degree of dependence (none, partial, or full) in bathing, eating, and walking and the degree of incontinence (none, bladder, or bowel). Cognitive impairment was defined as six or more errors on the Short Portable Mental Status Questionnaire. To describe the end-of-life trajectories of patients, data were analyzed from observational windows of time, beginning with the patients' dates of death and extending backward in time to 24 months before death. Each analytical window was 3 months in duration. For each of the functional measures, the probability of functional deterioration in the last 2 years of life in patients with (64%) and without (36%) cognitive impairment was also compared. **RESULTS:** The mean age at death was 84; 69% of patients were women. For patients with and without cognitive impairment, a prolonged, steady increase in the rates of functional dependence that were evident at least 1 year before death, rather than sudden increases in functional dependence shortly before death, characterized the functional trajectories. It was not possible for any of the four measures to detect a time point before death at which there was an abrupt decline in function likely to signal impending death. For each measure, patients with cognitive impairment declined earlier, were more likely than patients without cognitive impairment to have the maximal level of dependence in the 0- to 3-month window before death (e.g., 56% vs 30% for mobility,  $P < .001$ ), and were more likely to decline in the 2 years before death (e.g., 56% vs 36% for mobility,  $P < .001$ ). **CONCLUSION:** Patients with advanced frailty, with or without cognitive impairment, have an end-of-life functional course marked by slowly progressive functional deterioration, with only a slight acceleration in the trajectory of functional loss as death approaches. Patients with cognitive impairment have particularly high rates of functional impairment at the time of death. These results suggest that end-of-life care systems that are targeted toward patients with functional trajectories clearly suggesting impending death (such as the Medicare hospice benefit) are poorly suited to older people dying

with progressive frailty.

PMID: 12657068 [PubMed - indexed for MEDLINE]

49: J Contin Educ Nurs. 2003 May-Jun;34(3):122-7.

Nurses' needs for education on cancer and end-of-life care.

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**BACKGROUND:** Changes in cancer and end-of-life care require frequent assessment of educational needs of nurses. **METHODS:** The Nurse Oncology Education Program surveyed a random sample of Texas registered nurses about their continuing education practices, level of knowledge, and educational needs. **RESULTS:** The 352 nurses responding to the survey primarily obtained continuing education from workshops, inservice education, and independent studies citing cost, location, content, and length of course as influencing factors. Their cancer educational needs included clinical trials, genetics, complementary therapies, and pain management. Nurses' perceptions of end-of-life needs were for physical needs, "what to expect" concerns, and transition to palliative care. **CONCLUSION:** These findings provide specific direction for future continuing education programs about cancer and end-of-life issues for nurses.

PMID: 12772811 [PubMed - in process]

50: J Emerg Med. 2003 Jan;24(1):101-6.

Comment in:

J Emerg Med. 2003 Jan;24(1):87-9.

Prehospital resuscitation practices: a survey of prehospital providers.

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Numerous factors affect decision making in the prehospital provision of resuscitative care. This study was undertaken to determine current practices involved in the initiation, continuation and termination of resuscitative efforts, and the impact of advance directives, in the prehospital resuscitation setting. This cross-sectional mailed questionnaire surveyed 3807 members of the National Association of Emergency Medical Technicians. The study instrument included questions regarding the termination and withholding of resuscitative efforts in the prehospital setting, as well as survival rates, local protocols and compliance with advance directives. Of 1546 respondents (41% response rate), with a mean 9.0 years of experience, most (89%) indicated that they would withhold resuscitative efforts in the presence of an official state-approved advance directive. However, very few providers would withhold resuscitative

efforts if only an unofficial document (4%) or verbal report of an advance directive (10%) were available. Providers with more than 10 years experience were more likely to withhold resuscitation attempts in the presence of only a verbal report of an advance directive ( $p = 0.02$ , Chi-square), and were more likely to withhold resuscitation attempts in situations they considered futile ( $p = 0.001$ , Chi-square). Most (77%) respondents have local EMS guidelines for termination of resuscitation in the prehospital setting, but 23% of those consider existing guidelines to be inadequate. The majority of prehospital providers stated that they honor official state-approved advance directives, but do not follow directives from unofficial documents or verbal reports of advance directives. More experienced providers stated that they withhold resuscitative efforts more often in futile situations, or in the presence of unofficial advance directives. Advance directives should be utilized more uniformly among patients who wish to forgo resuscitative efforts in the event of cardiac arrest. Because many local protocols are judged to be inadequate, we support the institution of improved clinical guidelines regarding the prehospital termination of resuscitative efforts. Copyright 2003 Elsevier Science Inc.

PMID: 12554050 [PubMed - indexed for MEDLINE]

51: J Law Med. 2003 Feb;10(3):260-4.

Natural death in 2003: are we slipping backwards?

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PMID: 12649994 [PubMed - indexed for MEDLINE]

52: J Nurs Manag. 2003 May;11(3):189-96.

Pain and health-related quality of life among cancer patients in final stage of life: a comparison between two palliative care teams.

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A two-centred descriptive study was performed in order to describe and compare pain and health-related quality of life (HRQOL) among cancer patients, in their final stage of life. The patients were cared for by either a nurse-led palliative care team I (PCT I) or a physician-led palliative care team II (PCT II). Forty-six consecutive, stratified patients (PCT I,  $n = 21$  and PCT II,  $n = 25$ ) participated. The medical outcomes study short form 36 (SF-36) was used for evaluating HRQOL and the Pain-O-Meter for assessing pain. Patients' pain intensity, pain quality and HRQOL showed no significant difference between the two groups PCT I and PCT II. The patients from PCT I had significantly longer survival time ( $P = 0.017$ ) than those from PCT II. The different composition of

the teams being led by nurses or physicians is worth further research; both from the patient's and staff's viewpoint, there may also be cost-benefits worth examining.

PMID: 12694366 [PubMed - indexed for MEDLINE]

53: J Nurs Scholarsh. 2003;35(1):33-6.

Validation of the Spanish Life Support Preference Questionnaire (LSPQ).

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**PURPOSE:** To translate and validate the Life Support Preference Questionnaire (LSPQ) for use with Spanish-speaking adults, and to further validate the English version of the LSPQ. **METHODS:** Two samples were included: community-dwelling Hispanic and non-Hispanic adults who were monolingual or bilingual Spanish speakers, and an English-speaking sample, all living in south-central United States. Validation included calculation of internal consistency, stability, and alternate forms reliability estimates for two language versions of the LSPQ. Factorial validity was studied for both language versions and regression and t test analyses were done to explore ethnic differences in selection of the life support choices in the scale. **FINDINGS:** Both language versions of the LSPQ showed strongly supportive measurement properties. Differences were found between ethnic groups on four of the item choices, indicating that Hispanics in this sample preferred interventions to actively support life more than did the non-Hispanic adults. **CONCLUSIONS:** Both the English and Spanish versions of the LSPQ have been validated for use in research and practice. Additional validation will be necessary in other samples.

Publication Types:  
Validation Studies

PMID: 12701524 [PubMed - indexed for MEDLINE]

54: J Pain Symptom Manage. 2003 Apr;25(4):S53-62.

Maximizing benefits and minimizing risks in palliative care research that involves patients near the end of life.

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Research in end-of-life care is constrained more by pragmatic, social, cultural, and financial constraints than ethical issues that preclude the application of typical research methodologies. When normally accepted and ethically sound protections for subjects (especially for those who lack independent



decision-making) are in place, exclusion of patients with far advanced disease from research is in and of itself unethical. Involvement in research may have a therapeutic, anticomiogetic effect on dying patients and their families. Institutional review boards must be educated to evaluate research protocols involving this group of vulnerable patients with an eye toward assuring that ethical safeguards are in place, conflicts of interest are transparent and minimized, and that the proposed methodology has duly considered all practical exigencies so that resources and peoples' time and emotional investments are not squandered. Investigators and research review committees must be knowledgeable about placebo effects and under what types of circumstances their use is justifiable, preferred or requisite to fulfill both ethical and scientific imperatives. Examples of investigations using various research methodologies, along with their respective ethical considerations are provided.

Publication Types:

Review

Review, Tutorial

PMID: 12691697 [PubMed - indexed for MEDLINE]

55: J Pain Symptom Manage. 2003 Apr;25(4):369-75.

Correlation of the dose of midazolam for symptom control with administration periods: the possibility of tolerance.

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Although tolerance to midazolam is sometimes described in the palliative care literature, no studies have systemically examined the possibility. To explore the association between midazolam dose for symptom palliation and the administration period, a retrospective study was performed on 62 terminally ill cancer patients who required parenteral midazolam in the final three days of life. The mean maximum dose and administration period of midazolam were 38 +/- 45 mg/day (median = 24) and 10 +/- 19 days (median = 2.5), respectively. Thirteen patients (21%) received midazolam at a dose of 60 mg/day or more, and 13 patients (21%) received it for 14 days or longer. The maximum doses were significantly correlated with patient age ( $\rho = -0.32$ ,  $P = 0.012$ ) and the administration period ( $\rho = 0.47$ ,  $P < 0.01$ ); and were significantly higher in patients who received midazolam for 14 days or longer (74 +/- 63 mg/day vs. 28 +/- 34 mg/day,  $P < 0.01$ ). Multivariate analyses revealed that younger age ( $< \text{or} = 70$ ) and longer administration periods ( $> \text{or} = 14$  days) were independent determinants for a midazolam requirement of 60 mg/day or more (odds ratios [95% C.I.] = 0.091 [0.009 - 0.92],  $P = 0.042$ ; 11 [2.3 - 54],  $P < 0.01$ ; respectively). The significant correlation of midazolam doses with administration period suggests that the longer use of midazolam can result in the development of tolerance. This finding suggests that midazolam should be reserved for patients with limited prognoses.

PMID: 12691689 [PubMed - indexed for MEDLINE]



56: J Pain Symptom Manage. 2003 Apr;25(4):357-62.

Similarity and difference among standard medical care, palliative sedation therapy, and euthanasia: a multidimensional scaling analysis on physicians' and the general population's opinions.

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There is a strong controversy about the differences among standard medical care, palliative sedation therapy, and euthanasia in recent medical literature. To investigate the similarities and differences among these medical treatments, a secondary analysis of two previous surveys was performed. In those surveys, Japanese physicians and the general population were asked to identify their treatment recommendations or preferences for intolerable and refractory distress in the terminal stage. The options were standard medical care without intentional sedation, mild sedation, intermittent deep sedation, continuous deep sedation, and physician-assisted suicide (PAS)/euthanasia. Multidimensional scaling analysis mapped their responses. The physician responses were clustered into 3 groups: 1) standard medical care, 2) palliative sedation therapy including mild, intermittent deep, continuous deep sedation, and 3) PAS/euthanasia. The general population's responses were classified into 3 subgroups: 1) standard medical care, 2) mild and intermittent deep sedation, and 3) a group including continuous deep sedation and PAS/euthanasia. Physicians placed continuous deep sedation closer to mild and intermittent sedation, while the general population mapped it closer to PAS/euthanasia. In conclusion, physicians and general population can generally differentiate the three approaches--standard medical care, palliative sedation therapy, and PAS/euthanasia. We recommend that mild and intermittent deep sedation should be differentiated from standard medical care, and that continuous deep sedation should be dealt with separately from other types of sedation. Clear definitions of palliative sedation therapy will contribute to quality discussion.

PMID: 12691687 [PubMed - indexed for MEDLINE]

57: J Palliat Med. 2003 Feb;6(1):1-3.

Care near the end of life: what is unprofessional behavior?

Weissman DE.

PMID: 12710568 [PubMed - indexed for MEDLINE]

58: J Palliat Med. 2003 Feb;6(1):93-7.

Dobutamine for patients with end-stage heart failure in a hospice program?

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PMID: 12710582 [PubMed - indexed for MEDLINE]

59: J Palliat Med. 2003 Feb;6(1):86-91.

A student-initiated elective on end-of-life care: a unique perspective.

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Traditionally, curriculum change is a faculty responsibility. However, a first-year medical student, inspired by previous interactions with cancer patients and disillusioned with her education on the physician's role at the end of life, successfully initiated and sustained an end-of-life curriculum change. This article briefly describes the Preceptorship on End of Life Care and then shifts focus to five key dilemmas associated with student-led curriculum change. These dilemmas include articulating the benefits of student-initiated curriculum change, securing resources for curriculum change, the use of peer versus faculty facilitators, determining whether to create an elective or required curriculum, when to offer the course, and how to transition to new student leadership. Recommendations for students/residents seeking to initiate curriculum change are provided, highlighting the need for a collaborative approach of faculty, community affiliates, and students for sustained success.

PMID: 12710581 [PubMed - indexed for MEDLINE]

60: J Palliat Med. 2003 Feb;6(1):69-75.

Comment in:

J Palliat Med. 2003 Feb;6(1):5-6.

Hospice and nonhospice nursing home residents.

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OBJECTIVE: To compare hospice residents in nursing homes with residents who are noted as end-stage, but not in hospice programs. DESIGN: Descriptive comparison of the outcomes reported on Minimum Data Set (MDS) for all residents admitted to Missouri nursing homes in 1999. SETTING: Nursing homes. PARTICIPANTS: Residents of nursing homes designated as either hospice or end-stage on admission MDS. MEASUREMENTS: Percentage of hospice residents having various conditions as

compared with other end-stage residents. RESULTS/CONCLUSIONS: Overall the clinical conditions of both hospice and nonhospice end-stage residents were similar. A greater percentage of hospice residents were found to have living wills, DNR orders, and cancer, and to be in moderate or severe pain. Hospice and nonhospice residents experienced similar time from admission to death or discharge (20 and 36 days, respectively). Based on the clinical condition of the two groups, it would appear that there are limited clinical reasons for the low utilization of the hospice benefit in nursing homes. The increased prevalence of advance care planning may lead toward use of hospice or may result from hospice enrollment. Hospice services seem to be thought of more frequently for residents with cancer and residents experiencing pain. Nursing homes must recognize their role as caregivers to the dying before palliative care is seen as a need for nursing home residents. Nursing homes need education in determining when a patient is appropriate for palliative care as only 4% are designated as end of life, and only 2% are shown to be receiving hospice care in hospice-contracted facilities.

PMID: 12710577 [PubMed - indexed for MEDLINE]

61: J Palliat Med. 2003 Feb;6(1):59-68.

Perceptions of "good palliative care" orders: a discursive study of cancer patients' comments.

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Patients' perceptions regarding Good Palliative Care (GPC) orders, a form of advance directives, were sought, and issues inherent in their promotion as policy were identified. Semi-structured interviews with 23 oncology-clinic outpatients, focused on end-of-life decision making, were tape-recorded, transcribed, and analyzed using discursive-analytical techniques. Most patients were unfamiliar with the term GPC orders, preferring the familiar "do-not-resuscitate" orders. GPC orders were negatively perceived as vague, beyond the individual's control, implying dependency on others, and failing to reduce suffering. Positive perceptions of GPC orders saw them as counteracting the impersonality of medical procedure and asserting the value of the whole patient within a social context. Participants' comments on a draft copy of a GPC order form suggest that they view consultation as beneficial, but that a standardized form may be impersonal and inappropriate. The structure and content of the GPC order form constitute it as a quasilegal document that may confuse and disempower patients, and function to protect the interests of the medical profession in the guise of promoting patient autonomy. The potential benefits attributed to GPC orders are achievable without the adoption of a blanket policy that depersonalizes and bureaucratizes the dying process, and may be less than sensitive to individual patients' needs.

PMID: 12710576 [PubMed - indexed for MEDLINE]

62: J Palliat Med. 2003 Feb;6(1):45-57.

Comment in:

J Palliat Med. 2003 Feb;6(1):7-9.

The challenges and opportunities in providing end-of-life care in nursing homes.

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Approximately 20% of deaths in the United States occur in nursing homes. That percentage is expected to increase as the population continues to age. As a setting for end-of-life care, nursing homes provide both challenges and opportunities. This article examines factors that impede the delivery of high-quality end-of-life care in nursing homes, such as inadequate staff and physician training, regulatory and reimbursement issues, poor symptom management, and lack of psychosocial support for staff, residents, and families. In addition to discussing hindrances to providing end-of-life care, this article explores characteristics of nursing homes and their staff that support the care of terminally ill residents. Also included is an overview of models for delivering end-of-life care in nursing homes, including provision of hospice services, specialized palliative care units, and consultation services. Finally, this article discusses educational programs and current educational initiatives to enhance end-of-life care in nursing homes.

PMID: 12710575 [PubMed - indexed for MEDLINE]

63: J Palliat Med. 2003 Feb;6(1):5-6.

Comment on:

J Palliat Med. 2003 Feb;6(1):69-75.

Back to basics in nursing home care.

Keay TJ.

Publication Types:

Comment

Editorial

PMID: 12710569 [PubMed - indexed for MEDLINE]

64: J Palliat Med. 2003 Feb;6(1):19-31.

Issues in end-of-life care: patient, caregiver, and clinician perceptions.

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CONTEXT: Review of published research indicates the need to better incorporate patient and caregiver perceptions when providing end-of-life (EOL) care. Although considerable research regarding patient and caregiver experience of EOL has been done, little research has studied patients, caregivers, and clinicians as a connected system. OBJECTIVE: To study the perceptions of patients, caregivers, and physicians who are already connected with one another in an EOL care experience. DESIGN: Qualitative study consisting of in-depth, open-ended, face-to-face interviews and content analysis. SETTING: Community family practice residency programs in rural and urban settings in the Affiliated Family Practice Residency Network of the Department of Family Medicine, University of Washington School of Medicine. PARTICIPANTS: Forty-two patients and 39 caregivers facing EOL were interviewed either alone or together after referral by their physicians. Additionally, results of previously published findings from interviews with 39 family practice faculty were included. OUTCOME MEASURES: Perceptions of participants on EOL issues. RESULTS: Participants identified four primary issues related to their experience of EOL care: awareness of impending death, management/coping with daily living while attempting to maintain the management regimen, relationship fluctuations, and the personal experiences associated with facing EOL. Participants expected their physicians to be competent and to provide a caring relationship. CONCLUSIONS: Awareness of these crucial patient and caregiver EOL issues and expectations and how they differ from clinician perspectives can assist clinicians to appropriately explore and address patient/caregiver concerns and thereby provide better quality EOL care.

PMID: 12710572 [PubMed - indexed for MEDLINE]

65: J Palliat Med. 2003 Feb;6(1):33-6.

Palliation and survival in metastatic tumors compressing the cauda equina: a 19-year radiotherapeutic experience.

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PURPOSE; Radiotherapy (RT) offers a means of promoting an acceptable quality of life in people with incurable cancer. We reviewed our radiotherapeutic experience of metastatic tumors compressing the cauda equina (MTCCE) because large case series and achieved palliation in these patients are infrequently documented in the literature. METHODS: Seventy-six individuals undergoing RT for MTCCE were identified from a 19-year period (1981-1999). Treatment responses and survival were assessed. RESULTS: Pain relief was complete in 94%, partial in 3%, and not achieved in 3% of the 32 evaluated patients. Complete resolution of impaired sensation in the lower limbs occurred in three cases, and of anal or bladder sphincter dysfunction in three persons also. Among the 28 evaluable individuals with lower extremity motion impairment, 11 (39%) were nonambulatory and 17 (61%) were ambulatory following treatment. The overall median survival was 3 months; the survival rate at 1 year was 18% and at 3 years 8%.

CONCLUSION:

Although long-term survival is not to be expected, the usefulness of RT for palliation of MTCCE may be trusted.

PMID: 12710573 [PubMed - indexed for MEDLINE]

66: J Palliat Med. 2003 Feb;6(1):37-44.

Medical residents' perceptions of end-of-life care training in a large urban teaching hospital.

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**BACKGROUND:** Contemporary medicine has begun to reemphasize the importance of palliative and end-of-life-care. This shift requires a commensurate change in physician education to provide adequate palliative care training. The present research assessed medical residents' perceptions of their clinical and educational experiences in palliative care training as provided by a large urban teaching hospital. **METHODS:** All graduating third-year residents in internal medicine, family medicine, and social pediatrics at Montefiore Medical Center were asked to participate in a brief telephone survey. The survey assessed residents' experiences in caring for patients who were dying or had died, and their evaluation of faculty supervision, clinical rotations, and academic activities. **RESULTS:** Fifty-five residents (90%) were surveyed. They reported caring for few patients at the end of life over their 3 years of training (median of 10 inpatients who died, one outpatient who died, and three outpatients who were potentially terminally ill). Furthermore, the majority of residents gave poor ratings to clinical supervision and to clinical rotations where they were likely to evaluate dying patients (intensive care units and oncology), with only 16% of residents reporting that they had received very good or outstanding palliative care training. **IMPLICATIONS:** In order to provide adequate palliative care education to future physicians, residency programs must strategically target hospital training units, enhance the quality of palliative care supervision and training that residents receive, and increase the number of dying patients they care for in ambulatory care and nonhospital settings. Recommendations for change are discussed.

PMID: 12710574 [PubMed - indexed for MEDLINE]

67: JAMA. 2003 May 7;289(17):2238-45.

Hospice use among Medicare managed care and fee-for-service patients dying with cancer.

McCarthy EP, Burns RB, Ngo-Metzger Q, Davis RB, Phillips RS.

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CONTEXT: For most patients aged 65 years or older with cancer, hospice services are uniformly covered by Medicare. Hospice care is believed to improve care for patients at the end of life. However, few patients use hospice and others enroll too late to maximize the benefits of hospice services. OBJECTIVES: Because type of insurance may affect use, we examined whether patients with Medicare managed care insurance enrolled in hospice earlier and had longer hospice stays than patients with Medicare fee-for-service (FFS) insurance. DESIGN AND SETTING: Retrospective analysis of the last year of life using the Linked Medicare-Tumor Registry Database in 1 of 9 Surveillance, Epidemiology, and End Results program coverage areas. PATIENTS: A total of 260 090 Medicare beneficiaries aged 66 years or older diagnosed with first primary lung (n = 62 117), colorectal (n = 57 260), prostate (n = 59 826), female breast (n = 37 609), bladder (n = 19 598), pancreatic (n = 11 378), gastric (n = 9599), or liver (n = 2703) cancer between January 1, 1973, and December 31, 1996, and who died between January 1, 1988, and December 31, 1998. MAIN OUTCOME MEASURES: Time from diagnosis to hospice entry and hospice length of stay for patients enrolled in FFS vs managed care plans after adjusting for patient demographics, tumor registry, year of hospice entry, and type and cancer stage. RESULTS: Of the 260 090 patients, most were men (59%), white (85%), and enrolled in FFS (89.7%). Only 54 937 patients (21.1%) received hospice care before death. Hospice use varied by type of primary cancer ranging from 31.8% of patients with pancreatic cancer to 15.6% with bladder cancer. Managed care patients were more likely to use hospice than FFS patients (32.4% vs 19.8%,  $P < .001$ ). Among hospice patients, median (interquartile range) length of stay was longer for managed care vs FFS patients (32 days [11-82] vs 25 days [9-66],  $P < .001$ ). After adjustment, managed care patients had higher rates of hospice enrollment (adjusted hazard ratio [HR], 1.38; 95% CI, 1.35-1.42) and had a longer length of stay (adjusted HR, 0.91; 95% CI, 0.88-0.94) vs FFS patients. Managed care patients were less likely to enroll in hospice within 7 days of their death (18.6% vs 22.6%,  $P < .001$ ) and somewhat more likely to enroll in hospice more than 180 days before death (7.8% vs 6.1%,  $P < .001$ ); the results for each of the 8 cancer diagnoses were similar. Hospice enrollment and length of stay among managed care vs FFS patients differed significantly by region. CONCLUSION: Medicare beneficiaries enrolled in managed care had consistently higher rates of hospice use and significantly longer hospice stays than those enrolled in FFS. Although these differences may reflect patient and family preferences, our findings raise the possibility that some managed care plans are more successful at facilitating or encouraging hospice use for patients dying with cancer.

PMID: 12734135 [PubMed - indexed for MEDLINE]

68: JAMA. 2003 May 7;289(17):2278.

MSJAMA. Physician-assisted suicide.

Rajkumar R.

Publication Types:  
Editorial

PMID: 12734141 [PubMed - indexed for MEDLINE]



69: JAMA. 2003 May 7;289(17):2279-81.

MSJAMA. Legal status of physician-assisted suicide.

Battle JC.

University of Pennsylvania School of Medicine, Philadelphia, USA.

PMID: 12734142 [PubMed - indexed for MEDLINE]

70: JAMA. 2003 May 7;289(17):2282.

MSJAMA. Moral and practical challenges of physician-assisted suicide.

Lorenz K, Lynn J.

Veteran Affairs Greater Los Angeles Healthcare System, Los Angeles, Calif, USA.

PMID: 12734143 [PubMed - indexed for MEDLINE]

71: JAMA. 2003 May 7;289(17):2283.

MSJAMA. The legal and political future of physician-assisted suicide.

Palmer LI.

University of Louisville, Louisville, Ky, USA.

PMID: 12734144 [PubMed - indexed for MEDLINE]

72: Lancet Oncol. 2003 May;4(5):312-8.

The use of opioids and sedatives at the end of life.

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Opioids and sedative drugs are commonly used to control symptoms in patients with advanced cancer. However, it is often assumed that the use of these drugs inevitably results in shortening of life. Ethically, this outcome is excused by reference to the doctrine of double effect. In this review, we assess the evidence for patterns of use of opioids and sedatives in palliative care and examine whether the doctrine of double effect is needed to justify their use. We conclude that patients are more likely to receive higher doses of both opioids and sedatives as they get closer to death. However, there is no evidence that



initiation of treatment, or increases in dose of opioids or sedatives, is associated with precipitation of death. Thus, we conclude that the doctrine of double effect is not essential for justification of the use of these drugs, and may act as a deterrent to the provision of good symptom control.

Publication Types:

Review

Review, Tutorial

PMID: 12732169 [PubMed - indexed for MEDLINE]

73: Melb Univ Law Rev. 1999 Apr;23(1):161-83.

Advanced directives, the right to die and the common law: recent problems with blood transfusions.

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The Australian common law suffers from a lack of judicial authority on the right to die, in particular the right of patients to make anticipatory decisions to refuse treatment. Recent cases concerning the right of patients to refuse life-saving blood transfusions have highlighted the need for a substantial judicial clarification of this area. This article critically examines one of the most recent Australian cases in detail and compares its approach with those from other common countries. After taking this comparative analysis the article puts forth a common law model of anticipatory decision-making and examines how that model might work in the context of current legislative frameworks.

PMID: 12678066 [PubMed - indexed for MEDLINE]

74: Mich Nurse. 2002 Mar;75(3):4.

End-of-life care legislation signed into law.

Moore J.

PMID: 12747304 [PubMed - indexed for MEDLINE]

75: Nephrol Nurs J. 2003 Feb;30(1):59-63.

ESRD Workgroup Final Report Summary on End-of-Life Care: recommendations to the field.

Robert Wood Johnson Foundation.

In 1997, The Robert Wood Johnson Foundation launched a national program

Promoting Excellence in End-of-Life Care with a mission of improving care and quality of life for dying Americans and their families. We soon realized that the metaphor of a jigsaw puzzle seemed apt in describing our efforts to expand access to services and improve quality of care in a wide range of settings and with diverse populations. No single approach would suffice--a variety of strategies, models of care, and stakeholders are necessary to successfully complete the picture. This monograph represents one aspect of our work and one piece of the puzzle of ensuring that the highest quality of care, including palliative care, is available to all seriously ill patients and their families.

PMID: 12674951 [PubMed - indexed for MEDLINE]

76: Nephrol Nurs J. 2003 Feb;30(1):58.

Insight into the ESRD Workgroup Final Report Summary on end-of-life care.

Dinwiddie LC.

PMID: 12674950 [PubMed - indexed for MEDLINE]

77: Nurs Educ Perspect. 2003 Mar-Apr;24(2):86-90.

Oncology nursing education: nursing students' commitment of "presence" with the dying patient and the family.

Walsh SM, Hogan NS.

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During an elective oncology nursing course, students expressed uncertainties about activities that would offer patient and family support during end-of-life care. Following a chaplain's lecture, students in a class reaction paper identified appropriate nurse responses and actions that would offer supportive care to the dying patient and the family. Six processes were extracted from student comments. A core category was identified as the importance of "nurse presence" at the bedside of the dying patient.

PMID: 12743978 [PubMed - indexed for MEDLINE]

78: Nurs Ethics. 2003 May;10(3):236-7.

Medical technology, end-of-life care and nursing ethics.

Pang SM.

Publication Types:  
Editorial

PMID: 12762458 [PubMed - in process]

79: Nurs Forum. 2003 Jan-Mar;38(1):33-5.

A conversation with the family caretaker of a dying man.

Lyneham J.

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PMID: 12743972 [PubMed - indexed for MEDLINE]

80: Nurs Times. 2003 Apr 8-14;99(14):34-7.

District nurses' referrals to home-based palliative nursing services.

Fellowes D, Goodman M, Wilkinson S, Low J, Harvey F.

This study investigated district nurses' considerations of the Marie Curie Nursing Service. Most saw the primary service as respite care and referred patients to it during late stages of illness rather than palliative phases. The MCNS is valued, but confusion exists about appropriate referral times and the services provided. Improvement in communication and education is needed. The provision of this home palliative nursing service helps to promote the principle of palliative care in optimising the quality of life of patients who have life-limiting diseases and their families.

PMID: 12718284 [PubMed - indexed for MEDLINE]

81: Nurse Educ. 2003 May-Jun;28(3):111-20.

End-of-Life Nursing Education Consortium Curriculum: An Introduction to Palliative Care.

Sherman DW, Matzo ML, Panke J, Grant M, Rhome A.

The purpose of this article is to present the foundation for the End-of-Life Nursing Education Consortium (ELNEC) curriculum. Foundational content focuses on the need to improve end-of-life care, the role of nursing in providing quality care, and the basic principles of palliative care, all presented within a quality-of-life (QOL) framework. Teaching strategies are presented that allow undergraduate nursing faculty to teach their students how to respond in both a professional and personal manner to end-of-life issues.

PMID: 12792274 [PubMed - in process]

82: Nursing. 2003 Apr;33(4):17.

How Buddhism influences pain control choices.

Smith-Toner M.

California State University in Fullerton, USA.

PMID: 12722701 [PubMed - indexed for MEDLINE]

83: Omega (Westport). 2001-2002;44(1):57-76.

Compliance with patients' end-of-life wishes by nursing homes in New York City with conscience policies.

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Nursing home patients have a constitutional right to refuse treatment. The Patient Self-Determination Act confirmed that right. State laws address the obligations of health care providers and facilities to honor that right. The New York State law is more specific than those of many other states. It allows exemptions for "reasons of conscience" and imposes a number of requirements on nursing homes claiming such an exemption, including the transfer of a patient to a home that will honor an end-of-life wish. This study, conducted by FRIA, investigated the refusal of some nursing homes in New York City to carry out patients' end-of-life wishes because of conscience-based objections. The study also investigated the willingness of homes which did not have such policies to accept patients transferring from a home with a policy so that the patient's end-of-life wishes would be honored. Implications for administrators, policy makers, and regulators are discussed.

PMID: 12583360 [PubMed - indexed for MEDLINE]

84: Omega (Westport). 1999-2000;40(2):323-33.

The development of the physicians' end-of-life care attitude scale.

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The Physicians' End-of-Life Care Attitude Scale (PEAS) was developed as an outcome measure for palliative care education. PEAS assesses the willingness of medical trainees to care for dying patients. Sixty-four Likert-type questions were created on the basis of discussions with focus groups of medical trainees, then administered to sixty-two medical students and residents. Total PEAS scores as well as personal preparation and professional role subscales (where higher scores indicated greater concern) possessed excellent internal consistency and reliability. In addition, there were substantial correlations between PEAS

scores and the CA-Dying scale, a measurement of laypersons' fears about interacting with dying persons. Thus, PEAS adequately assesses the unique communication concerns of physicians in training regarding working with dying persons and their families. Correlations between PEAS scores and age were negative, while those who had experienced the death of a loved one had higher PEAS scores than those who did not. This suggests that for some persons, life experiences may lessen difficulties in dealing with dying persons, while for others, personal losses may exacerbate such concerns. The utility of PEAS in evaluating the efficacy of palliative care education as well as its potential to measure medical trainee's willingness to care for the terminally ill is discussed.

PMID: 12577894 [PubMed - indexed for MEDLINE]

85: Oncologist. 2003;8(1):108-22.

Living as a cancer surpriser: a doctor tells his story.

Knuti KA, Wharton RH, Wharton KL, Chabner BA, Lynch TJ Jr, Penson RT.

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Shortly before his death in 1995, Kenneth B. Schwartz, a cancer patient at Massachusetts General Hospital (MGH), founded the Kenneth B. Schwartz Center. The Schwartz Center is a non-profit organization dedicated to supporting and advancing compassionate health care delivery, which provides hope to the patient, support to the caregivers, and sustenance to the healing process. The center sponsors the Schwartz Center Rounds, a monthly multidisciplinary forum where caregivers reflect on important psychosocial issues faced by patients, their families, and their caregivers and gain insight and support from fellow staff members. We tell the story of one physician with incurable non-small cell lung cancer (NSCLC) who had an unexpectedly favorable response to an experimental treatment while receiving it as a part of his palliative care. His unique insight provides an opportunity to elucidate some of the issues that arise from living both as a patient-caregiver and as a cancer "surpriser." When caregivers face their own cancer, their reflections as patient-caregivers offer an internal perspective on the illness experience and help us as fellow caregivers to better understand and support all patients who face serious illnesses, both those who are colleagues and those who are not. Just like any patient with cancer, patient-caregivers experience the dramatic changes in health, daily life, and perspective that come with serious illness. Within the context of a life-threatening illness, caregiver-patients and their families search for new meaning as they face an uncertain future and address the issues of life and death. In addition to such processes, patient-caregivers with cancer also find that their own medical knowledge and their colleagues' reactions shape their experiences and to an extent separate them from those of other patients.

PMID: 12604737 [PubMed - indexed for MEDLINE]

86: Palliat Med. 2003 Mar;17(2):92-3.

Comment on:

Palliat Med. 2003 Mar;17(2):97-101; discussion 102-79.

The euthanasia debate and a new position paper from a Task Force of the EAPC: a helpful reappraisal or a retreat into obfuscation?

Forbes K, Hanks G; Task Force of the EAPC.

Publication Types:

Comment

Editorial

PMID: 12701846 [PubMed - indexed for MEDLINE]

87: Palliat Med. 2003 Mar;17(2):94-6.

Palliative care and the euthanasia debate: recent developments.

Huxtable R, Campbell AV.

Publication Types:

Editorial

PMID: 12701847 [PubMed - indexed for MEDLINE]

88: Palliat Med. 2003 Mar;17(2):222-4.

Euthanasia, regulation and slippery slopes.

Ashcroft R.

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PMID: 12703486 [PubMed - indexed for MEDLINE]

89: Palliat Med. 2003 Mar;17(2):180-3.

Comment on:

Palliat Med. 2003 Mar;17(2):97-101; discussion 102-79.

The position statement and its commentators: consensus, compromise or confusion?

Campbell AV, Huxtable R.

Publication Types:

Comment

Editorial

PMID: 12701849 [PubMed - indexed for MEDLINE]

90: Palliat Med. 2003 Mar;17(2):97-101; discussion 102-79.

Comment in:

Palliat Med. 2003 Mar;17(2):180-3.

Palliat Med. 2003 Mar;17(2):92-3.

Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force.

Materstvedt LJ, Clark D, Ellershaw J, Forde R, Gravgaard AM, Muller-Busch HC, Porta i Sales J, Rapin CH; EAPC Ethics Task Force.

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PMID: 12701848 [PubMed - indexed for MEDLINE]

91: Palliat Med. 2003 Apr;17(3):270-82.

The development of palliative care in national government policy in England, 1986-2000.

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Palliative care is an established and expanding speciality, important in many areas of service delivery within health and social services and the voluntary sector. Traditionally, palliative care is viewed as most closely linked to cancer services. National government policy has an inevitable impact on the organization and provision of such services. As part of a wider project, an investigation of the content and development of English government policy relating to palliative care was carried out. The development of policy follows a cycle that has no closure; it takes place within changing contexts, between multiple organizations and across sectors. Data collection involved the collation and close examination of policy documents and other documents that demonstrably influenced policy. This was in order to identify a national view of policy intentions for palliative care. In total, 53 policy documents were examined. The analysis revealed a number of pertinent issues relating to shifts in funding policies and an evolving definition of palliative care. There is an increasing recognition in the policy documents of the need for palliative care to extend beyond the traditional focus on cancer services and terminal illness. In tandem, is an increasing recognition of the need for partnership between sectors, reflected in more recent health and social services legislation.

PMID: 12725481 [PubMed - indexed for MEDLINE]

92: Palliat Med. 2003 Apr;17(3):289-92.

Dying in the community: general practitioner treatment of community-based patients analysed by chart audit.

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PMID: 12725483 [PubMed - indexed for MEDLINE]

93: Patient Educ Couns. 2003 May;50(1):43-9.

Patient centered decision making in palliative cancer treatment: a world of paradoxes.

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Patient centered palliative cancer care would imply, first, the introduction of psychosocial endpoints when evaluating treatment and making decisions. Second, patient control would have to be enhanced by information giving and increased decision involvement. We have indicated that paradoxes exist when a patient centered approach is advocated in the context of palliative cancer care. So-called patient oriented outcomes, like quality of life, once introduced seem to be disregarded by many patients themselves and survival is given a more important weight. Likewise, physicians seem to be inclined to treat patients aggressively for little benefit rather than providing supportive care. Both parties seem to prefer to do something actively to maintain a semblance of control over the disease process. Giving treatment, even if aggressive, is a way to avoid the confrontation with the little efficacy that the physician has to offer to incurable cancer patients. This mechanism is reflected in the content of conversations in palliative care. Patient centered care would imply that patient control and autonomy are enhanced. However, again paradoxically, many patients seem to want to avoid information and leave the decisions to be made by their doctors. Physicians, then, follow such wishes while paying more attention to aggressive therapy than to the notion of watchful waiting. This may help to avoid the painful confrontation with bad news. Dilemmas then remain. Patients wishing to maintain hope and avoid emotional impact of a full understanding of their prognosis may rather not be informed brusquely about prognosis or the aims of supportive therapy and forced to make an informed decision. However, by giving more aggressive, maybe even futile, treatment, and withholding supportive care patients may receive less than 'quality end-of-life care'. Therefore, information about less intrusive strategies should still be given in a cautious manner, while regarding the patient's defenses respectfully.

PMID: 12767584 [PubMed - in process]



94: Tenn Med. 2003 Mar;96(3):138-9.

A patient's right to die: physician-assisted suicide.

Regan J, Alderson A.

Tennessee Department of Mental Health and Developmental Disabilities, Nashville, USA.

Publication Types:

Review

Review, Tutorial

PMID: 12666376 [PubMed - indexed for MEDLINE]